

Presumed Consent in Organ Donation: Is The Duty Finally Upon Us?

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Abstract

In recent years there has been a renewed interest in presumed consent systems for organ donation. The UK's Organ Donation (Presumed Consent and Safeguards) Bill of 2004 proposed a sweeping change in the law in the form of an opt-out system for the donation of cadaver organs. The Organ Donation Taskforce in 2008 later examined the idea of presumed consent at length, before concluding that our current organ procurement system needs a radical overhaul. Most recently, the Organ Donation (Presumed Consent) Bill of 2009 ("the 2009 Bill") provided the most comprehensive proposal yet for an opt-out organ donation system in the United Kingdom. Is it now time to take this controversial issue seriously? If the 2009 Bill provides a window into the future, what practical and ethical difficulties will this new presumed consent legislation impart upon our current organ procurement system? This article will provide an overview of the previous attempts in the U.K. to implement an opt-out system for organ donation, before examining in detail the content of the 2009 Bill as a potential template for a new presumed consent law. Finally, some sweeping amendments to the 2009 Bill will be suggested, and it will be concluded that a new piece of legislation may change our national and international views of organ donation for the better.

Keywords: organ donation; presumed consent; legislation; bioethics

1. Introduction

As recently as 2004, the Organ Donation (Presumed Consent and Safeguards) Bill was put before the Commons. Its opening paragraph stated as follows:

‘A Bill to provide for the removal of organs for transplantation purposes, after death has been confirmed in a person aged 16 or over, except where a potential donor previously registered an objection or where a close relative objects.’¹

Although the 2004 Bill did not proceed much further in the legislative process, it presented the opportunity for Parliament to discuss this controversial and important matter in depth. The 2009 Bill was presented to Parliament in March 2009 with the same objective in mind.² The Department of Health also set up the Organ Donation Taskforce, which, in 2008, published an independent report into the implications of a presumed consent system in the UK. The Taskforce came to the conclusion that the current opt in

¹ Can be accessed under ‘previous bills’ at <http://services.parliament.uk/bills/>.

² Up until November 2009, the 2009 Bill had been discussed in Parliament and was awaiting a date to begin its consideration in a public Bill committee. Parliament then dissolved in November 2009 and the Bill was not re-introduced.

system may simply need a radical overhaul, as it was found that only a small proportion of the general public were aware of the existence of the Organ Donor Register.³ However, the Report found that approximately 60% of the population ‘would support a change to an opt out system, as long as it was properly implemented to ensure that the rights of vulnerable groups were protected’.⁴

Below is a detailed examination of the 2009 Bill as a template for a new presumed consent system, and the procedural and ethical difficulties that it would present.

2. The 2009 Bill

The 2009 Bill is the most recent attempt in the U.K. to introduce a presumed consent system for cadaver organ donation. It is the most detailed Bill to date. As a potential template for future presumed consent Bills, the relevant provisions of the Bill read as follows:

1 Presumption of consent for donation of organs.

(1) Where a person has not during his lifetime registered an objection to his body, or any specified part of his body, being donated for transplantation after his death it shall be presumed that he consented to such a donation -

(a) except where the designated person is satisfied, on the basis of information provided by a person’s spouse or partner (or, where there is no spouse or partner, by a parent or child of the deceased), that the person had expressed an objection to donation that had not been registered; or

(b) to proceed with the donation would cause distress to the person’s spouse or partner (or, where there is no spouse or partner, to a parent or child of the deceased).

(2) In the case of a person aged under 18 years there shall be no presumption of consent, and donation may proceed only if the designated person is satisfied that such donation is in accordance with the wishes of that person or with the consent of that person’s parents or other primary carer.

2 Register of objection to transplantation of organs

(1) There shall be a register of those persons who object to their organs being used for transplantation.

³ See ‘The potential impact of an opt out system for organ donation in the UK’, an independent report from the Organ Donation Taskforce, published November 2008 at www.dh.gov.uk/organdonationtaskforce, at page 34.

⁴ *Ibid.*, paragraphs 1.6 and 1.7 at page 4, and also page 16 under ‘ethical issues’.

(2) Where it is intended to remove any organ of a deceased person for the purposes of transplantation, the register established under subsection (1) must be consulted to determine whether the person had registered an objection.

(3) Where a person is found to have registered an objection under subsection (2) no removal of organs may be permitted.

(4) Regulations shall make provision relating to the register established under subsection (1) and in particular in connection with -

- (a) the manner in which a person is able to register an objection;
- (b) the manner in which the register must be consulted before the removal of organs for transplantation.

3 Death of person donating organs

No organs may be removed from a person whose organs are intended to be used for transplantation unless two registered medical practitioners have satisfied themselves that the person is dead.

4 Interpretation

In this Act –

“designated person” means the person with control and management of the hospital or institution concerned;

“death” means the irreversible loss of the capacity for consciousness, combined with irreversible loss of the capacity to breathe, determined by permanent cessation of heartbeat or, where the heartbeat is maintained artificially, by brain stem tests carried out in accordance with the criteria set out by the Conference of Royal Colleges (and “dead” shall be construed accordingly).

3. Procedural Difficulties

The 2009 Bill outlined a potentially sweeping piece of legislation. At first glance, procedural difficulties spring up from many angles, the first of which concerns the exact scope of any potential legislation.

Section 1(1) states that a person must register an objection to his body, or a specified part of his body, being donated for transplantation. It seems strange that a *whole* body can be donated for transplantation, rather than simply ‘organs’ or ‘tissues’, unless of course a person’s body is donated to some other place for some other reason, such as medical research. The broad nature of this subsection may be misconstrued to mean that a person can consent to his whole body simply being ‘given away’ for an undisclosed purpose. Many may feel that medical research centres may take advantage of

such a provision. The subsection is also unclear as to what constitutes ‘a specified part of his body’. The 2009 Bill did not include blood transfusions, bone marrow donations, and the many other smaller regenerative parts of the human body that can be safely transferred into another person. Similarly, the term ‘transplantation’ alone does not stipulate that another *patient* will receive the deceased’s organ; it could potentially be ‘transplanted’ anywhere! There may need to be specific elaborations under section 1 if a similar Bill were to be drafted.

Section 1(1)(a) stipulates that a doctor must be satisfied that the information provided by the deceased’s spouse, partner, parent or child correctly represents the deceased’s objection to donation. This is a difficult policy to implement when one considers the importance of patient autonomy. Concerns about overriding familial views have already been canvassed in relation to consenting to organ donation,⁵ but the crux of the 2009 Bill was to give respect to a *patient*’s decision to partake (or, rather, not to partake) in a particular medical procedure.⁶ The only way in which a doctor can be satisfied that the deceased’s objection is truly his own, is to check on the relevant register to see if the deceased has expressly objected to the donation of his organs upon his death. Unless a stricter provision is in place, any similar Bill will simply allow the views of the deceased’s relatives to exert the same absolute power over organ donation that we see today. This discussion also presents the question: is the listed group of potential relatives in the 2009 Bill wide enough? What of those deceased patients who have no such relatives? Will consent in these cases simply be presumed without searching for distant relatives or close friends who could speak on the deceased’s behalf?

Inevitably, section 1(1)(b) also provides the same named relatives - spouse, partner, parent or child - with the power to object to organ donation if they were to experience ‘distress’ as a result of the procedure. This ‘soft’ provision may be frustrating to some. The U.K. has been apprehensive in earlier decades to draft Bills or reforms regarding presumed consent programs in organ donation.⁷ This apprehension may be a response to the public concern that relatives will feel shocked that their deceased spouses and children will be ‘harvested’ - without any familial consent - for their hearts, lungs, livers, and kidneys before their bodies have even turned cold. It may be this overhanging threat of unethical behaviour on the part of medical professionals that is responsible for the rather ‘soft’ approach under section 1(1)(b). Through allowing them to veto the deceased’s wish to donate, Parliament appear to want to include the deceased’s relatives in the whole donation process because, in their time of grief, they may not be able to bear the idea of their relative’s organs being taken away. It depends on the approach that Parliament wish to take, and the impact on donation the wish to make, as to whether the provision under section 1(1)(b) is acceptable or damaging to the ultimate goal of a presumed consent Bill.

⁵ See Bernard Teo, ‘Is the adoption of more efficient strategies of organ procurement the answer to persistent organ shortage in transplantation?’ (1992) 6 *Bioethics* 113-29, 127; V. English and A. Sommerville, ‘Presumed consent for transplantation: a dead issue after Alder Hey?’ (2003) 29 *Journal of Medical Ethics*, 147-52; and I. Kennedy, R.A. Sells, A.S. Daar, R.D. Guttman, R. Hoffenberg, M. Lock, J. Radcliffe-Richards, N. Tilney, and the International Forum for Transplant Ethics, ‘The case for “presumed consent” in organ donation’ (1998) 351 *The Lancet*, 1650-2.

⁶ See also C.A. Erin and J. Harris, ‘Presumed consent or contracting out’ (1999) 25 *Journal of Medical Ethics* 365-6.

⁷ The earliest failed attempt in the U.K. was the Transplantation of Human Organs Bill 1993.

Sections 2(2) & (3) of the 2009 Bill state that the intention to remove an organ can only be acted upon after the objection register has been consulted; if the patient has registered his objection, the donation can not go ahead. These provisions are, of course, to be read in conjunction with sections 1(1)(a) & (b). It appears that a combination of the deceased's wishes and the views of the relatives will be considered by the doctor before a decision is to be made. Therefore, if the deceased objected to donation in the required way, the deceased's view stands. If the deceased consented (or was presumed to have consented), the relatives can veto this. There is no provision in the 2009 Bill which stipulates that the views of the relatives are not to be considered by the doctor in any circumstances. As a result, Parliament give the impression that the provisions and the relatives of the deceased are to work in harmony to reach an agreement on donation. The Organ Donation Taskforce presented an interesting view in this regard. After questioning the public about presumed consent and opt out systems, there was a feeling that a system of presumed consent would relieve families of the burden of making a decision in the absence of any indication as to the deceased's wishes. However, the Taskforce found: "this a somewhat paternalistic view, at odds with the ethos of today's NHS. Further, our evidence from donor families was that they stressed the importance to them of being involved in the decision to donate and of being allowed to make the decision that was *right for them* at the time."⁸

4. Commentary on Substantive Difficulties

The 2009 Bill inevitably reignited some traditional controversies regarding organ donation and transplantation. Two provisions in particular cause significant moral concern.

Section 1(2) states that persons under 18 are *not* presumed to be consenting to organ donation and it lies to the parents or the carer of the child to consent on his behalf. This provision sees a reversal of the *presumed* consent initiative underpinning the previous sections, and it does not change the current law. If the parents of the child do consent to donation, the doctor must be satisfied that the child would have wanted this. As examined in section 1(1)(a) above, it is difficult enough for a doctor to be sure that the relatives of an adult patient are representing the deceased's views, let alone being able to accurately deduct a child's true consent through the voice of a parent or carer. Perhaps this is the wrong direction for a new Bill to take? There are significant shortages of infant and child organs, and in instances where a child is tragically taken at such a young age, it is difficult to approach the grieving parents to request an organ donation. Perhaps of all groups, children should be the most eligible for strict presumed consent donation programs? The most controversial part of this provision is not related to what *is* included, but what is excluded. Parliament does not appear to mention any particular groups of society who could be automatically exempt from presumed donation. Both Belgium and Singapore take the opportunity to exclude certain vulnerable donors from their presumed consent programs, such as mentally disabled adults, non-citizens, and Muslims. In addition, the 1969 Renal Transplantation Bill in the U.K. provided exclusions for persons

⁸ See paragraph 8.4 at page 17 of the Organ Taskforce Report, at f.n. 3 above. Emphasis added, to highlight the importance of the wishes of the relatives over the deceased's autonomy, the latter being a fundamental right for any patient in medicine.

who, at the time of death, were suffering from mental illness or mental handicap, minors, those over 65, prisoners, and permanent residents in institutions for the aged, disabled or handicapped.⁹ What about adults in the U.K. with strong religious preferences or mental and physical disabilities? Is it correct that they are to be 'presumed' to be consenting when ordinarily they would be deemed reluctant or incapable to consent to such medical procedures? The provisions of the 2009 Bill may take advantage of such individuals.

The second provision to cause a great moral problem is embedded in section 3, which states that no organs may be removed from a cadaver unless two registered medical practitioners have satisfied themselves that the person is dead. Section 4 proceeds to explain the definition of 'death' as the irreversible loss of the capacity for consciousness and the capacity to breathe, determined by permanent cessation of the heartbeat. Brain stem tests are then to be carried out in accordance with the criteria set out by the Conference of Royal Colleges. There have been several calls in the past for Parliament to provide a statutory definition of 'death',¹⁰ and Parliament appear to have 'borrowed' a definition for the purposes of the 2009 Bill,¹¹ but there are long-known controversies concerning the true time of brain-stem death. It has been submitted that since actual death occurs before the brain-stem tests, there is an urgent need for some criterion to establish the moment of death.¹² By leaving such criteria to be ascertained by the Conference of Royal Colleges, Parliament may be expressing their desire to detach themselves from this thorny issue, leaving the uncertainties in medicine to continue.

Because patients are deemed to be 'alive' right up until two brain stem tests have been performed, no procedures are allowed to be carried out on the patient that would not be in his or her best interests, and this includes life support to simply 'maintain' organs.¹³ An even more complex moral dilemma appears under section 4:

'[brain stem death can be] determined by permanent cessation of heartbeat *or*, where the heartbeat is maintained artificially, by brain stem tests ...'

When the heartbeat of a patient is maintained artificially because he or she has no chance of recovery, this is known as elective ventilation, and it would enable doctors to remove 'living' organs from 'deceased' patients. The 2009 Bill, by allowing for deceased patients

⁹ B. New, M. Solomon, R. Dingwall, and J. McHale, 'A Question of Give and Take: Improving the Supply of Donor Organs for Transplantation' (1994) *King's Fund Institute*, at pages 56-64.

¹⁰ See B. New, *ibid.*, at pages 56-64, who argues that new legislation of this kind would require a statutory definition of death. See also: I.H. Kerridge, P. Saul, M. Lowe, J. McPhee, and D. Williams, 'Death, dying and donation: organ transplantation and the diagnosis of death' (2002) 28 *Journal of Medical Ethics*, 89-94; and E.R. Koppleman, 'The Dead Donor Rule and the Concept of Death: Severing the Ties That Bind Them' (2003) 3(1) *American Journal of Bioethics*, 1-9.

¹¹ See The British Transplantation Society and the Royal Colleges, who developed the criteria for establishing death, which are now contained in the Department of Health's Code of Practice for the Diagnosis of Brain Stem Death, HSC 1998/035, para 1: "...it is recommended that the definition of death should be regarded as 'irreversible loss of the capacity for consciousness, combined with irreversible loss of the capacity to breathe'. The irreversible cessation of brain stem function will produce this clinical state and therefore brain death equates with the death of the individual."

¹² M. Jones, 'Elective ventilation of potential organ donors: The Legal Background' *British Medical Journal* 1995; 310: 717-18; and Emily Jackson, 'Medical Law: Text, Cases and Materials', (2006), Oxford University Press, at page 717.

¹³ Also see David P.T. Price, 'Organ Transplant Initiatives: the Twilight Zone' (1997) 23 *Journal of Medical Ethics*, 170.

to include electively ventilated patients, was promoting the idea that elective ventilation could be used as a means of acquiring human organs. There may be a great danger here. Normally, patients are placed on life support machines in order for doctors to carry out tests. Once it is established that the patient is dead, the ventilation is no longer necessary. Parliament was suggesting, in essence, that since all individuals are presumed to be consenting to organ donation, it would be appropriate and correct to maintain brain-stem dead patients on a life support machine solely to acquire his or her organs for transplantation. Moving brain-dead individuals with no hope of recovery from one ward/department to another with attached ventilator equipment solely to attain their organs could be viewed as deeply undignified.¹⁴ There is also a concern that the patient may only be in a persistent vegetative state rather than brain stem dead, which would mean that when the organs are taken, and the machine is switched off, the patient was still alive. This ‘maintaining of cadavers’ for the purposes of organ donation will be difficult for some to accept. There are concerns that this controversial procedure will: a) lead to a cruel delaying of death; b) persistent vegetative state (PVS) patients may be mistakenly diagnosed as brain-stem dead; c) a person close to natural death may develop PVS; d) it is distressing for relatives to see their loved one’s body being kept ‘alive’ for ‘salvaging’ purposes; and e) unless it can be proved that such a procedure is in the best interests of the patient, it is currently illegal. In the words of Lord Browne-Wilkinson in *Airedale NHS Trust v Bland*:

“If there comes a stage where the responsible doctor comes to the reasonable conclusion that further continuance of an intrusive life support system is not in the best interests of the patient, he can no longer lawfully continue that life support system: to do so would constitute the crime of battery and the tort of trespass to the person.”¹⁵

If elective ventilation is simply deemed to be illegal because of the lack of consent, Parliament may be able to manoeuvre around this conundrum as a result of *Brown*,¹⁶ which implies that a patient, when ‘consenting’ to his organ donation under the 2009 Bill, can also consent to the battery which takes place on his body when his organs are taken from him in his ventilated state. Although it is almost impossible to argue that the process of electively ventilating a brain-dead patient for the purposes of gleaning his organs for transplantation is in his best interests, if both brain-stem tests have been carried out, technically the patient is already dead, and so the ‘best interests’ test becomes obsolete.¹⁷

Since the 2009 Bill required that the patient be brain-stem dead, this does rule out the possibility of persistent vegetative state patients being accidentally ‘murdered’ for their organs. However, PVS and other patients do seem vulnerable under the provisions of the 2009 Bill. At the slightest hint of brain death, relatives of the patient may find themselves fending off vulture-like practitioners, preparing the nearby life support

¹⁴ See J.V. McHale, ‘Elective Ventilation - Pragmatic Solution or Ethical Minefield?’ (1995) 2 *Professional Negligence* 24, and Park et al (1993) ‘Organ Donation’ *British Medical Journal*, 306, 145; and David P.T. Price, ‘Organ Transplant Initiatives: the Twilight Zone’ (1997), above at f.n. 13.

¹⁵ See Lord Browne-Wilkinson in *Airedale NHS Trust v Bland* [1993] A.C. 789, at page 884.

¹⁶ *R v Brown* [1993] 2 All ER 75.

¹⁷ See David P.T. Price, ‘Organ Transplant Initiatives: the Twilight Zone’ (1997), above at f.n. 13, and A. Nicholls and H. Riad, (1993) ‘Organ Donation’ *British Medical Journal*, 306, 517-518.

machine in morbid anticipation. The Organ Donation Taskforce made their concerns about this issue very clear when publishing the worries of the members of the public:

“The fear that you might not actually be dead, with doctors ‘jumping in too quickly’ before ‘someone is definitely gone’, was one that was widely expressed. A system of decision making which is based on respecting the known wishes of the patient is the one that is most likely to maintain the integrity of the relationship between doctors and patients and trust in the donation system.”¹⁸

The notion of ‘presumed consent’ can clearly spill over into the area of elective ventilation, and this is an ethical minefield that no one can cross safely. There may be room for medical personnel to take advantage of this controversial provision if it were to be re-submitted in a new Bill, and a re-drafting may be necessary to prevent any unethical practices. Ideally, elective ventilation and organ procurement should never cross paths, but some support has been found for such a combination. After all, the only way in which a dead patient can provide efficient organs is if he or she were to be kept alive. Solomon states that an electively ventilated patient is quite clearly a means of saving lives and reducing suffering.¹⁹ It has also been stated that while it would be difficult to argue that treatment which prolonged the process of dying was in the best interests of the patient, it might be possible to establish that the patient was so strongly committed to being an organ donor during her lifetime that elective ventilation would allow her final wishes about the fate of her body to be fulfilled.²⁰

5. Presuming Consent

The whole idea of presumed consent has been described as a fiction: unless a person consents, he has provided *no* consent.²¹ There are arguably three reasons why the doctrine of presumed consent does not sit well in the field of medicine. 1) it undermines patient autonomy; 2) it assumes knowledge on the part of the patient; and 3) it causes distress to relatives. Is it worth the ethical quagmire to implement such a policy?

Patient autonomy is a fundamental principle in medical care. The patient-doctor relationship is based on trust, and a presumed consent program of any nature takes the power away from the patient to *expressly consent* to a medical procedure. It has been suggested that by presuming consent, we are being disrespectful of individual autonomy and articulating a particular view of what is morally acceptable to do with a dead body when that person has not consented prior to death to such treatment after death.²² Parliament may be able to get away with presuming consent for smaller, less personal matters, such as unwanted physical contact on public transport, but the donation of our organs upon death is acknowledged by many to be a sacred gift, and to assume that all individuals are this altruistic will be seen by many as a step too far.²³ Not all of us give to charity, and not all of us exercise the same moral values, so why should we all be

¹⁸ See paragraph 8.2. at page 17 of the Organ Taskforce Report, at f.n. 3 above.

¹⁹ *Ibid.*

²⁰ Emily Jackson, ‘Medical Law: Text, Cases and Materials’, (2006), above at f.n. 12, at pages 716-7.

²¹ See in particular C.A. Erin and J. Harris, ‘Presumed consent or contracting out’ (1999), above at f.n. 6.

²² *Ibid.*

assumed to consent to donating parts of our body? Any new Bill will need to be drafted very tightly to ensure that the medical profession could not take advantage of the presumed consent doctrine, or ignore a deceased's wishes, which would be devastating to public support and trust if such neglectful practice was to be revealed.

The doctrine of presumed consent assumes not only that every individual in the land is consenting to a particular procedure, but that every such individual is aware of what he is consenting to. This is a dangerous assumption. There are many groups of people, from many cultures and backgrounds, who may not understand such a law. The influx of migrant workers in the UK from other European countries means that many of our inhabitants may have difficulty comprehending the new legislation. Others may not wish to be a part of the new law but do not understand how to register an objection, some may not have ever heard of the new law,²⁴ and others may be too lethargic to investigate the law.²⁵ Many individuals are simply ignorant of the law, and it would require a massive publicity crusade on the part of the Government to educate every relevant member of society about what will happen to their body and their organs in the event of their death. During this national publicity, it is also vital that the rationale behind any new Bill is not portrayed as the 'common altruistic standard of society'. Many people will not agree, or feel a part, of the broad moral assumption that everybody wishes to donate their organs upon death. Individuals may feel pressured into consenting to donation simply because the act of opting-out could be viewed as anti-social.²⁶

The taking away of a deceased's autonomy will inevitably leave many grieving relatives aghast. Harris argues that if organs do not go for donation, then the worms, or the fire, or sometimes the coroner, will get them in the end. Thus, it would be best to think of cadaver donation in such terms, as a duty the dead owe to the living, which costs them little or nothing to pay and which does huge amounts of good.²⁷ It may not be as simple as that. Organ donation is a contentious issue, and to be faced with a recently-deceased spouse or parent being taken directly from their bed and their organs extracted for another's use will leave many relatives wounded. How relatives are left feeling by a new law based on the provisions of the 2009 Bill will play a pivotal role in its success. If a new Bill was to be strict and extract organs without taking any heed to the views of the deceased's relatives, the publicity generated from this would make it difficult for the Government to gather public support. They might find a sudden and overwhelming number of objections to donation, causing a potential catastrophe for NHS Blood and Transplant, the UK's leading organ procurement agency. In light of these possibilities, Solomon makes an interesting distinction to autopsies:

²³ The Report of the Working Party on the Supply of Organs for Transplantation, chaired by Sir Raymond Hoffenberg, (1987) DHSS, London, states the following at page 6: "There would be a risk that organs might be removed when this had not been the wish of the person or their relatives. It does not in itself enlist the co-operation of doctors. We would prefer organ donation to be seen as a positive gift with the consent of relatives who in practice would always be approached."

²⁴ See K. Dyer, 'Increasing Organ Supplies: Legislate for "Enforced Choice" not "Presumed Consent"' *Medico-Legal Journal* (2008) Vol. 76 Part 2 56. at page 56.

²⁵ See further O. Hutchinson, 'Presumed Consent' *The Legal Executive Journal*, March 2008, page 30.

²⁶ For further discussion see Emily Jackson, 'Medical Law: Text, Cases and Materials', 2006, above at f.n. 12, at pages 720-1; and B. New, 'A Question of Give and Take: Improving the Supply of Donor Organs for Transplantation' (1994), above at f.n. 9.

²⁷ C.A. Erin and J. Harris, 'Presumed consent or contracting out' (1999), above at f.n. 6.

“Distress could certainly be caused to family members who wished to grieve without the knowledge or suspicion that the body of a loved one was being ‘mutilated’ - particularly if donation was conducted only under a ‘presumption’ that the deceased had given consent. It is worth noting, however, that the sensibilities of families are not taken into consideration in the case of a coroner’s autopsy. A large number of deceased individuals are subjected to invasive surgery, without the need for consent, to satisfy social imperatives.”²⁸

Perhaps we accept autopsies more easily because they are designed to bring comfort to the grieving family by filling in unanswered questions about our loved ones’ death. Organ donations merely benefit other people, and leave the grieving family feeling as though something has been taken from them in their time of grief. It is a difficult comparison to make, but it highlights a clear distinction between the casual societal consent to autopsies, and an almost ‘forced’ consent to organ donation.

6. Potential Amendments to The 2009 Bill

In light of the procedural and ethical difficulties in the 2009 Bill, a few suggestions will be put forward for a new Bill, in order to close the loopholes and add some clarity. It will be assumed that Parliament wish to take the middle ground in regards to presumed consent - not too harsh in their approach, but still hoping to make some sweeping changes.

In relation to the ambiguities regarding the term ‘transplantation’, the following amendment is put forward:

Section 1(1) Where a person has not during his lifetime registered an objection to his organs or tissues being donated for transplantation into another person after his death, it shall be presumed that he consented to such a donation.

This allows for patients to be clear on details such as what exactly can be taken, and how they will be used.

The current provisions under section 1(1)(a) & (b) regarding the power to consent and object appear to be rather lax, and fall heavily in favour of the deceased’s relatives. In order to place the power back into the hands of the doctor, the following stricter provision is recommended:

Section 1(1)(a) The designated person must consider the objecting views of a person’s spouse or partner (or, where there is no spouse or partner, by a parent or child of the deceased), but the views of the surviving relatives may not override the wishes of the deceased.

This stricter provision only allows for the deceased to object to the donation of his organs, thus preserving his autonomy. This may seem rather firm, but the doctor under the recommended provision can not completely reject the wishes of the relatives - he

²⁸ B. New, ‘A Question of Give and Take: Improving the Supply of Donor Organs for Transplantation’ (1994), above at f.n. 9.

must *consider* them. The end decision will be placed with the doctor, not the relatives, to retain the principle of patient autonomy, and to uphold the trust between patients and the medical profession as a whole. Another smaller amendment to this section could include 'close friends' of the deceased as part of the group of people who the doctor can consult, just in case no family members come forward to veto the presumed consent. This may happen in the case of an elderly patient, who's immediate family is untraceable.

Section 1(2) does not presume that children consent, unless an adult or carer does it for them. If this occurs, the doctor must be 'satisfied' that the child would have consented to donation, but it is difficult for a doctor to ascertain a child's true wishes unless he speaks to that child directly before death. Considering this, and combined with the shortage of paediatric organs, it is suggested that section 1(2) could be expanded and changed to provide the following:

Section 1(2) In the case of a person aged under 16 years, there is a presumed consent to donation on behalf of the parent or carer of that child. The parent or carer may register an objection to donation until the child reaches 16 years of age.

Section 1(3) In the event that the parent or carer has not registered a formal objection to organ donation but still objects to donation when the child is under 16 years of age, the doctor must discuss with the parent or carer of the deceased child what the wishes of the deceased's family would be.

In the case of children under 16, the parent can veto the consent by registering an objection. If no objection is registered on the national register, the doctor must liaise with the child's family to reach a donation decision. It would not be appropriate for a doctor to ignore the wishes of a parents when the child is under 16. When the child reaches the age of 16, a new Bill would treat that child as an adult for the purposes of organ donation.

A particularly controversial omission from the 2009 Bill is that regarding the automatic exclusion of certain groups of people from the presumed consent program. Vulnerable people, non-citizens, religious individuals, prisoners, and other groups of people may be inappropriate candidates for one reason or another. Therefore, another new subsection could be added under section 1:

Section 1(4): Registered citizens who are mentally impaired are exempt from the 'presumed consent' Act.

It is thought that those who are most unlikely to 'consent' are mentally impaired children and adults, non-citizens, and religious individuals. Mentally impaired individuals are generally thought to be incapable of consenting to a medical procedure, and so organ donation should be no different. It also seems unlikely that non-citizens would consent to donating their organs to a strange country. If our Government were to procure their organs upon their death - thus 'presuming' their kindness towards us as hosts - this could be seen as simply taking advantage of international visitors. Since religious individuals cannot be defined by statute, perhaps they can simply object to donation in the normal way?

The final area which, it seems, requires urgent amendment, is the one which stipulates that elective ventilation and the procurement of organs are somehow interlinked. This is a cause for concern for the simple reason that the provision may be open to being ‘stretched’ to satisfy demand. The issue is not with the procedure of elective ventilation in itself, but the idea that deceased patients can - and should - be kept alive by means of elective ventilation solely to procure their organs. If Parliament do not intend to portray this message, then section 4 of a new Bill could read:

Section 4: “death” means the irreversible loss of the capacity for consciousness, combined with irreversible loss of the capacity to breathe, determined by permanent cessation of heartbeat (and “dead” shall be construed accordingly).

By removing the term ‘maintained artificially’, this sends a clear message that the patient must not be on a life support machine when organ donation takes place. However, a deceased patient may still be maintained artificially for a considerable amount of time to preserve the quality of his organs, before his machine is switched off and his organs removed. Parliament may like to make it clear that this practice is not allowed. The following provision could be added to section 4:

The practice of maintaining of a brain-stem dead patient by artificial ventilation for the sole purpose to procure a patients’ organs is prohibited.

7. International Systems of Organ Donation

There are some interesting approaches to organ donation in the international arena which are worth considering. The most well-known system of presumed consent is that of Belgium, which was enacted in 1986 and updated in 2007. Their laws, which have been used as an example in many other countries, state that organs and tissues may be removed from the body of any person who is a Belgian National, or has lived in Belgium for six months, and who is recorded in the Register of the Population, unless it is established that an objection to such a removal has been expressed by the patient. This can be done through sending a formal objection to the local authority.²⁹ In Belgium in the late 1980’s, the number of donors rose from 15 to 40 per year over a 3-year period. Nationally, organ donation rose by 55% within 5 years despite a decrease in the number of organs available from road-traffic accidents. Individuals who wished to opt out of the scheme were able to register their objection at any Town Hall, but since 1986 less than 2% of the population have done so. A computerised register was able to store all of the objections easily.³⁰

There are clearly stark differences between the current provisions in the U.K. and Belgium. Firstly, in the Belgian legislation it is clear that both organs and tissues are eligible for donation under the presumed consent program, and it takes little to qualify as a ‘Belgium National’ for the purposes of organ donation. Secondly, children are allowed to object to donation in Belgium, meaning that they are *included* in the presumed consent

²⁹ The law is discussed in H. Nys (ed) ‘International Encyclopaedia of Laws: Medical Law, Belgium’, (2009). Also see A. Grubb, (2005) ‘Kennedy & Grubb’s Medical Law’ 3rd Edition. Oxford University Press at pages 1869-1870 for several other international perspectives.

³⁰ See further: I. Kennedy, ‘The case for “presumed consent” in organ donation’ (1998), above at f.n. 5.

program. Thirdly, the donor may express his objection to donation directly to the doctor, but the doctor does not have to take any account of the relatives' views, thus preserving the autonomy of the patient. Belgium operates a considerably strict policy; relatives of the deceased have no power to veto the presumed consent of the patient.

A much stricter policy applies in Austria, where organs can be removed from the patient provided that in his or her lifetime, he or she expressed no objection. The relatives of the deceased are allowed to object, but the doctors are under no obligation to seek their views. Other 'softer' schemes in France and Spain allow organ donation on the premise that the relatives are consulted in order to establish the views of the deceased.³¹ If the deceased has objected at any time in any way, the donation will not go ahead. Interestingly, a program in Singapore allows for the automatic exclusion of certain groups of people, such as non-citizens and Muslims.³²

If the U.K. Parliament wish to take a 'hard' approach such as that seen in Austria, distressed relatives should not be allowed to veto the wishes of the deceased and the autonomy of the patient should remain paramount.³³ If Parliament wish to take a 'softer' approach and simply make it easier for relatives to consent to donation in their time of grief such as in France and Spain, then the wording under section 1(1)(b) of the 2009 Bill will allow this to happen. From looking at the international picture, we can see that full consideration, but limited power, should be given to the relatives of the deceased if a system wishes to respect patient autonomy. Additionally, provisions need to be made for individuals who cannot usually consent because of learning difficulties or disabilities; a presumed consent in these instances would be viewed as either invalid or grossly unethical. Critique's of the Austrian system may argue that individuals who simply forget to remove their name from the register should not be presumed to be consenting, but we already see this problem with opt-in systems: there may be numerous individuals on a country's Register today who, for whatever reason, may have changed their mind about donating organs in the time passed since they applied. A consultation with family members in the event of the individual's death may correct this matter. There are, however, reasons to prefer an improved opt in system as a means of removing uncertainty, as we see in the U.S., Ireland, and Canada. For example, if a person had not registered their wishes formally, in the absence of a clear conversation taking place a family could only guess what the deceased would have wanted. Might it be easier for relatives to make such a difficult decision if the deceased was already listed on the register and did not feel strongly enough during his life to voluntarily remove himself from the database? They may find it much easier to consent to donation if it was revealed that the deceased was comfortable enough about the prospect of having his or her name on the Organ Donor Register not to remove it.

³¹ Research in France has shown that the views of relatives are always sought, and the presumed consent program simply exists on paper: see Bernard Teo, 'Is the adoption of more efficient strategies of organ procurement the answer to persistent organ shortage in transplantation?' (1992), above at f.n. 5.

³² B. New, 'A Question of Give and Take: Improving the Supply of Donor Organs for Transplantation' (1994), above, at f.n. 9.

³³ The World Medical Association stated in October 2006 in their Statement on Human Organ Donation and Transplantation that a potential donor's wishes are of paramount importance, whether he agrees to donate, or refuses. See the WMA General Assembly, South Africa, www.wma.net.

8. Conclusion

The brave move by Parliament to draft such a detailed presumed consent organ donation Bill provides a ray of hope for the many transplant candidates awaiting an organ transplant in the U.K. There will always be ethical difficulties when a piece of legislation proposes to operate on the presumption that every member of society holds the same moral ideals and aspires to live by the same altruistic values, but if carefully drafted, a new Bill founded upon the provisions of the 2009 Bill could initiate a major shift in the way our society views organ donation.

The 2009 Bill offered a somewhat ‘soft’ approach to presumed consent, giving the majority of the power to object to the organ donation to the relatives of the deceased. The doctor must simply be ‘satisfied’ that the relatives have witnessed the deceased objecting to such a procedure, or the relatives must expressly state to the doctor that they would suffer distress as a result of the procedure. The suggested amendments (above) offer a slightly stricter approach, placing more power into the hands of the doctor when no objection has been registered. Parliament may have intended to start ‘soft’ in this area in order to lessen the potential backlash from the general public. After all, it is a controversial idea. However, plenty of support can be found, including from the British Medical Association, which, back in 2000, offered their views in support of a presumed consent organ donation program:

“It is reasonable and appropriate to assume that most people would wish to act in an altruistic manner and to help others by donating their organs after death. Studies show that the majority of people would be willing to donate but only a small number of these are on the NHS Organ Donor Register or carry a donor card. Given that the majority of people would be willing to donate, there are good reasons for presuming consent and requiring those who object to donation to register their views. It is more efficient and cost effective to maintain a register of the small number who wish to opt out of donation than of the majority who are willing to be donors. This represents a more positive view of organ donation which is to be encouraged.”³⁴

It may be true that many people are willing to donate, but perhaps this could be proven with a nation-wide Governmental survey?

One advantage to a presumed consent organ donation program which can not be denied is the easing of the burden upon the shoulders of grieving relatives to consent to donation only moments after they are faced with the untimely death of their loved one. To *presume* consent allows for the relatives of the deceased to simply ‘confirm’ that donation can go ahead, as opposed to undertaking the decision alone. It is a difficult decision to make only moments after losing a spouse, partner, parent or child, but knowing that the deceased has not formally registered an objection to donation could make the whole experience of donation for the grieving relatives much easier to cope with.³⁵ The presumed consent program also gives objecting individuals a formal

³⁴ BMA Medical Ethics Committee, ‘Organ donation in the 21st Century: time for a consolidated approach’, (BMA 2000).

³⁵ I. Kennedy, ‘The case for “presumed consent” in organ donation’ (1998), above at f.n.5; Emily Jackson, ‘Medical Law: Text, Cases and Materials’, (2006), above at f.n. 12, at pages 722-3; and B. New, ‘A

mechanism for registering their views.³⁶ The only potential issues we may still have to contend with are the ways in which it is appropriate to treat both dead and dying patients. Hopefully, the former will be treated in a way which the relatives are satisfied, and the latter will not be seen as ‘organ resources’ by a profession which is in desperate need for scarce organs.

Question of Give and Take: Improving the Supply of Donor Organs for Transplantation’ (1994), above at f.n. 9.

³⁶ V. English and A. Sommerville, ‘Presumed consent for transplantation: a dead issue after Alder Hey?’ (2003), above at f.n. 5.